

Compassion in Action: A Look at Caregiving in America

Each day in the United States, more than five million older individuals receive some kind of assistance from family members, friends and neighbors that allows them to live in their own homes outside of the nation's formal system of care, which includes nursing homes and other long-term care facilities. Often these "informal" caregivers are the lifelines that their older relatives and friends rely on, not only for daily care, but to bring them critical information about the community services and national programs available to assist them.

The month of May is annually proclaimed by the President of the United States as Older Americans Month, a time to acknowledge the nation's older citizens and examine the issues that affect them most. Focusing the nation's attention on its older citizens has never been more appropriate, given that the average American is living longer than ever before. This fact, coupled with the changing face of the nation's health care delivery system, means more Americans of all ages are dealing with the issue of how to care for an older family member or friend who needs ongoing assistance. The fact is that caregivers play a critical role in enhancing the quality of life for older individuals, and they need to be supported in their efforts as much as possible.

It is with this reality in mind that the U.S. Department of Health and Human Services' Administration on Aging (AoA), in conjunction with the extensive, nationwide aging network, has selected, "Caregiving: Compassion in Action," as this year's Older Americans Month theme. AoA and the aging network have selected this theme in an effort to cast a spotlight on the issue of caregiving and its impact on all Americans.

During the month and throughout the coming year, AoA and the aging network—which includes AoA's regional offices, more than 700 state and area agencies on aging, more than 200 tribal organizations, and thousands of aging services providers and volunteers nationwide—will be making efforts to inform caregivers about the extensive network of services and resources available to assist them and the older people in their own communities to whom they provide care. However, providing a link for older individuals to these resources is just one of many tasks the average caregiver performs on any given day.

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What Is Caregiving?

According to AoA, there is a distinction between what is recognized as the formal system of care and informal caregiving. Informal caregiving is defined as unpaid care provided to a person aged 65 or older who has an impairment that limits that person's independence and requires some level of ongoing assistance.

Research indicates that the bulk of long-term care in the United States is provided by informal caregivers. In fact, only one in five older persons needing long-term care lives in a nursing home. The remainder live in their own communities, thanks to the support of informal caregivers who routinely assist with a range of activities.

These caregiving activities usually fall into one of four categories—emotional support, direct service provision, linkage with the formal service sector and financial assistance. Studies have shown that adult children now provide more emotional support to their older parents than ever before and that most caregivers are involved in providing direct services to those they care for as well. These direct services range from what are called instrumental activities of daily living, such as transportation, shopping and housecleaning, to activities of daily living, which include bathing, dressing, eating and moving about.

Who Are America's Caregivers?

In a world fraught with images and concerns about the disintegration of the traditional American family and its effects on society, it is heartening to note that the family remains as committed as ever to caring for dependent, older family members. For the most part, today's primary informal caregiver in the United States is a wife or, if the wife is not available, an adult daughter. In the absence of a wife or daughter to assume primary responsibility, another relative usually steps in. Where no family members are available, older persons in need of assistance will turn to their friends and neighbors.

The average age of family caregivers in the United States is 46 years. Interestingly, and contrary to stereotypes that portray older individuals as always being the recipients of care, 12 percent of the caregiving population is aged 65 or older. According to AoA, many Americans do not realize that at least 20 percent of the nation's informal caregiving force is made up of the "young-old" caring for the "old-old." Women represent 75 percent of the caregivers in the U.S., but husbands are by far the older caregivers, with 42 percent aged 75 or over.

Where Can Caregivers and Those They Serve Go for Assistance and Information?

AoA and the aging network work together to provide a full range of services to assist older and disabled people living either in their own homes or in residential care settings. This home and community-based system of care strives to meet the needs of older persons and their caregivers in every region or community across the country.

Generally speaking, the services provided through the nation's home and community-based system of care can be divided into two categories—services that assist older persons directly, which often assist the primary caregiver indirectly, and services that focus on supporting the caregiver. Services that assist older persons directly may include personal care, homemaker and chore services; congregate and home-delivered meals; adult day care; rehabilitative care; assisted transportation; home health care; housing options; and consumer protection and advocacy. Services designed especially for caregivers include support and assistance in identifying home and community-based care services for their loved ones or friends, as well as respite care for themselves and assistance for older individuals raising children.

Older individuals and caregivers can get information on home and community-based care and other support services in their communities by contacting their State Unit on Aging or local Area Agency on Aging. These organizations are generally listed in the city or county government sections of the telephone directory under "Aging" or "Social Services."

Individuals who have difficulty identifying the aging network organization closest to the person in need of assistance can call the Eldercare Locator toll-free at 1-800-677-1116, Monday through Friday from 9:00 a.m. to 11:00 p.m., EST. Administered by the National Association of Area Agencies on Aging and the National Association of State Units on Aging, the Eldercare Locator is a public service of AoA and can be reached from anywhere in the country to identify local public and private resources and services available to assist older people and their caregivers.

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